

*The Oklahoma Attorney General's
Task Force Report on the state of:*



*End-of-Life
Health Care
2005*

W.A. Drew Edmondson

**"IT IS IMPORTANT THAT FAMILY, CARE GIVERS
AND FRIENDS KNOW AND UNDERSTAND YOUR
HEALTH CARE DECISIONS."**

-W.A. DREW EDMONDSON



Our Hopes for Change: *A letter from the attorney general*

When asked about our expectations for health care near the end of our lives, most of us share the same vision: to be free of pain; to be at home surrounded by family and friends; and to have our wishes known and honored. However, in Oklahoma today, most of us die in a health care facility, without palliative care, and isolated from loved ones.

I am concerned why Oklahoma health care consumers are not receiving what they hope for at the end of life. One of my responsibilities as attorney general is consumer protection. I want to partner with health professionals, state leaders and consumers to eliminate the existing legal, policy and educational barriers to good quality end-of-life care in Oklahoma.

To address this goal, in April, 2004, I announced the formation of a Task Force made up of 15 Oklahoma legal and health professionals charged to investigate end-of-life care in our state and report their findings to me. The task force meetings included more than 70 members of an advisory committee as well as the task force members. In these meetings, state leaders heard from panels of experts in area of concern including advance directives, nursing facilities, hospitals, hospices, care for children, and other general issues.

The result of this year of intensive research includes specific recommendations to improve end-of-life care available to Oklahomans, as well as identifying important issues for further study. This report will be distributed to members of the Oklahoma legislature, agency directors, and to interested opinion leaders and consumers across the state.

As a senior elected public official, I can imagine no finer legacy as a public servant than to reduce human suffering in our state. This report is the beginning of an ongoing commitment by my office and an invitation to state leaders to join me in addressing this vital issue which, ultimately, affects us all.

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Our Work Begins:

A letter from the task force



Dear Attorney General Edmondson:

In April, 2004, you invited 15 health and legal professionals to join you on a task force to investigate barriers to quality health care for Oklahomans nearing the end of their lives. You also gathered more than 70 opinion leaders from around the state to serve as members of an advisory committee to this task force. These leaders included members of the Oklahoma legislature, the judiciary, state agency directors, health professionals and consumers from nursing facilities, hospitals, hospices and educational institutions.

With your leadership as Chair, the task force listened to experts address serious barriers to advance decision-making for end-of-life care, and availability of competent care in Oklahoma health care settings. We followed your charge to review these barriers and recommend solutions for consideration by our state policy makers and health professionals.

Based upon our work, we are submitting specific recommendations that we believe will form the basis for action. We hope these recommendations will be supported by your office and others who are committed to representation of our fellow Oklahomans at this most vulnerable time in life. Our recommendations include requests for Attorney General opinions to clarify the laws regarding advance directives in our state. We are also suggesting increased education for health professionals in nursing facilities, hospitals and hospice environments.

Particularly, we are requesting that you authorize continuation of the task force through April, 2006, so that we may proceed to address important issues that remain to be considered, including care for persons diagnosed with Alzheimer disease, the mentally ill, developmentally disabled, and cultural diversity in treatment of terminal illness. We commend you and your office for taking a leadership role in monitoring end-of-life issues in Oklahoma and we urge you to continue this leadership.

On behalf of the Task Force, we look forward to your response to this initial report of our findings and encourage you to contact us or other members of the task force to discuss our conclusions or to assist in any way in your consideration of these issues.

Sincerely,

Gary Johnson, M.D., and Linda Edmondson, LCSW
Co-Chairs, Attorney General's Task Force to Improve End-of-Life Care in Oklahoma

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Executive Summary



By Task Force Co-chair
Linda Edmondson, LCSW

The Attorney General's Task Force to Improve End-of-Life Care met eight times from May to November, 2004. It began by looking at advance directives in Oklahoma. These documents are a foundation to good end-of-life care because they allow persons to make their wishes known in advance. The task force found current state law and documents complicated and sometimes restrictive. Recommendations are to clarify the decision-making powers of proxies named in different documents, and to create guides for consumer education.

Next the task force considered end-of-life care in nursing facilities, where over a quarter of Oklahoma's elderly die. The task force learned that federal guidelines focused on increasing function may conflict with palliative care goals at the end of life. Nursing facilities often are faced with uncertainty regarding residents' wishes and their ability to provide appropriate end-of-life care. Recommendations focus on increased education for staff, more choice of hospice, and guidelines for developing a plan of care for residents at the end of life.

Hospitals were considered because almost half of Oklahoma deaths occur in a hospital. The task force learned that hospital care is focused on cure, and changing the goals of care to palliative or comfort care is difficult for health care professionals as well as families. Recommendations target increased education and implementation of palliative care throughout hospital settings.

The task force was interested in hospice care, often considered the ideal end-of-life experience. More than a quarter of Oklahomans over 65 die with hospice service. However, the task force heard concerns about the large number of hospices in the state, and their ability to provide good quality services. Recommendations call for increased oversight of hospice providers, reporting of hospice consumer data, and creation of an ombudsman program.

In the future, the task force hopes to examine end-of-life issues for several special populations. The many unique concerns of dying children and their families were acknowledged in a task force meeting. Recommendations include a consumer guide

for parents, increased attention by hospitals, hospices and other institutions to the special needs of parents and children at the end of life, increased professional training and a resource center for pediatric palliative care.

General recommendations made by the task force include, most importantly, the distribution of the initial report and follow up for action. Equally important, the attorney general is asked to seek funding to continue the work of the task force for another year to explore the many issues recommended for further study.

Creation of two documents was also recommended: a uniform set of end-of-life physician orders which could follow a patient from one setting to another, and a uniform patient transfer form to convey complete medical information between facilities. The task force also recommended that the two physician licensing boards require continuing medical education in end-of-life and palliative care for all licensed physicians.

A special note about pain management issues at the end of life: While pain control was initially one of the issues for task force consideration, another group, the Advisory Council on Pain Management, was established by the legislature in the spring of 2004. Because of the focused work of that Council, the attorney general's task force did not consider pain management issues in depth this year. The task force intends to examine the Advisory Council's report and actions before deciding what additional information and recommendations may be needed.

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**MEMBERS OF THE ADVISORY
COMMITTEE LISTEN TO A PANEL
DISCUSSION.**

**ATTORNEY GENERAL EDMONDSON
LEADS THE TASK FORCE'S INITIAL
MEETING IN APRIL 2004.**



General Task Force Recommendations

1. The task force recommends that the attorney general deliver this report to the following persons and work with them to implement the recommendations:

- The Governor of Oklahoma and executive staff
- Members of the Oklahoma House and Senate
- Relevant state boards and agencies
- Relevant associations and professional groups
- Interested state and community coalitions, groups, facilities, and agencies

2. The task force recommends that the attorney general seek state funding to continue the work of the Task Force until at least April, 2006.
3. The task force recommends that it work with other interested parties to create a uniform instrument for end-of-life physician orders, similar to the POLST (Physician's Orders for Life-Sustaining Treatment) form in Oregon, that could be used at home, in hospice, nursing homes, and hospitals, and by emergency workers in transportation.
4. The task force recommends that a uniform patient transfer form be developed by the Oklahoma State Department of Health, to be used when patients move between nursing homes and hospitals. This transfer form could be used with the POLST form to insure complete information is conveyed between facilities.
5. The task force recommends that the Oklahoma State Board of Medical Licensure and the Osteopathic Board of Medical Examiners require continuing medical education (CME) in end-of-life care, palliative care, and related bioethical issues, within 6 years, for all licensed physicians.

Section One:

Advance Directives



Directing End-of-Life Care in Advance of Incapacity

The first charge to the Task Force was to address the question “If I die in Oklahoma, will my wishes be known and honored?”

Oklahomans have the opportunity to complete three documents to direct their end-of-life care in advance of incapacity: Advance Directive for Healthcare, which contains both a living will and appointment of a health care proxy; Durable Power of Attorney for Health Care (DPOAHC), which appoints an agent to make medical decisions, and Oklahoma Do-Not-Resuscitate Consent, which addresses only cardio-pulmonary resuscitation (CPR). These documents are widely available from attorneys and from the Department of Human Services.

Two issues are particularly important in Oklahoma in relation to planning for incapacity. Oklahoma law assumes all incapacitated persons want to be fed artificially unless they give written instructions to the contrary. In addition, in Oklahoma the designation of a proxy or surrogate is important because there is no statutory hierarchy of decision-makers.

INTRODUCTION

Common concerns about advance planning and Oklahoma documents include:

- Because the Oklahoma Advance Directive covers only those with a terminal diagnosis and less than six months to live and those in a persistently unconscious state, the wishes of incapacitated people who don't fit those specific categories may not be followed.
- Oklahomans may not realize that Oklahoma statute assumes that every patient wants artificial nutrition and hydration if incapacitated, and therefore they may not take steps to make their wishes clear.
- In cases where the Oklahoma Advance Directive does not apply, as in cases of advanced Alzheimer's Disease or stroke, the DPOAHC can be used to make medical decisions. But in order for the proxy named in the document to make life-sustaining decisions, such as discontinuing tube feeding or dialysis, they must also be named as the patient's proxy under the advance directive. This is confusing and many people are unaware of this provision.

- According to Oklahoma law, everyone whose heart or breathing stops should receive cardiopulmonary resuscitation (CPR). If the patient is actively dying, if the CPR would be futile or if it would cause greater harm to the patient, a do-not-resuscitate (DNR) order may be appropriate and desired. The form available for a patient to indicate that they do not want CPR should be a near-death document. However, if such a document is not filled out, patients may be inappropriately resuscitated. Oklahomans may be unaware that they also require this document if they are certain they do not want CPR.
- If patients do not designate a proxy or surrogate in Oklahoma, there may be confusion as to their wishes. The family members that a patient assumes will be able make decisions for them may not be allowed to do so, and disagreements among family members may occur.

THE TASK FORCE MEETING

The Task Force heard from four panelists:

Nancy Kenderdine, professor of law at Oklahoma City University School of Law

Judy Shaw, attorney in private practice specializing in advance planning and estates

Sandra Bazemore, Vice President of Patient Services at Grady Memorial Hospital

Dr. Rosa Cintron, professor at the University of Oklahoma College of Education

Among the points made by the panelists:

- The United States Supreme Court has made a firm statement that patients are entitled to palliative care if they request it. The court also made it plain that providing pain medication to relieve pain is appropriate even if that medication may hasten death.
- The U.S. Supreme Court has also confirmed the right of all persons to refuse medical treatment. The best (but not the only) evidence of a person's wishes to terminate treatment is a written document.
- Attorneys in Oklahoma currently offer different opinions on the two most common documents used in advance planning for incapacity. The DPOAHC grants broad powers to a proxy, but authority to make life-sustaining treatment decisions is not among them unless the proxy is also named as a proxy in the Advance Directive. Practicing attorneys differ on how this problem is best resolved. One panelist recommended combining the documents in some way.
- The advance directive is legally in effect only when two physicians indicate the patient is terminally ill and will die within six months or is persistently unconscious. Thus many people who believe their proxy will be able to carry out their wishes if they are incapacitated will not be represented because they do not fall under the definition.
- Despite the protection that is given in the statute to the physician and other health care providers from civil and criminal liability for following the advance directive, some health care providers state that they are afraid to act under the directive. The concern is that the family members who disagree with the wishes of the patient may sue the providers. One panelist stated that she was not aware of a suit ever being filed in Oklahoma based

on a doctor honoring an advance directive. A provider could also be sued for failure to follow the advance directive.

- Panelists reiterated the importance of education for the public about the laws and documents in Oklahoma, especially the issues related to artificial hydration and nutrition. Education was also recommended for attorneys in order to make care planning part of all estate planning. Educational efforts should also be aimed at health care providers about the meaning, use and limitations of the documents.
- Because some feel that the advance directive in Oklahoma is not very “user friendly,” there are questions as to whether the form must be followed. The statute says that any advance directive should be in substantially the same form as that in the statute. There is no case law or Attorney General Opinion defining what would constitute substantially the same form.
- Despite the efforts that some patients make to plan in advance for their incapacity, many times these documents are not available when needed, are ignored or otherwise obstructed, and interventions from attorneys or other advocates are needed to assist the proxy in carrying out the intentions of the patient.
- Panelists frequently cited the need for better communication among family members, between patients and physicians and between family and physicians. Also a concern is a statewide understanding of the law and documents, so that what happens in one community is also going to happen in another.
- Culture and belief systems are important in understanding death and advance planning. In traditional cultures, the extended family is important and authority may be vested in the parents. Children may be expected to care for the elders and that responsibility should not be given to others. It may be seen as a sign of disrespect to ask parents to give a power of attorney to an adult child. Patients may desire to personalize the relationship with their care providers before having end-of-life conversations with them. These are a few of the examples of why end-of-life planning must be culturally relevant.
- To promote advance planning, it is necessary to use all the languages spoken in Oklahoma and to use all the means available to reach cultural and ethnic minorities.

DISCUSSION

The task force members and panelists asked questions, made comments and discussed the issues raised by the panelists. The issue of why people do not sign such documents was addressed by a physician who felt that medical schools did not teach doctors how to have such conversations. In addition, it is a lengthy process if done properly, and it is difficult to receive reimbursement. Some felt that education was the key, others felt the documents needed to be simplified.

Task force members discussed a recent article in the Hastings Center Report. The article contends that living wills don't work because few people have them, and they have limited

effect on medical decision-making at the end of life. The authors believe that a Durable Power of Attorney is a much more effective document because it is easier to fill out and more apt to be followed.

Some prefer the Five Wishes document and wondered if it could be considered "substantially the same form" as the Oklahoma form. Another form discussed was the POLST document used in Oregon. It is a set of physician orders, more specific than an advance directive, which can communicate end-of-life treatment decisions to emergency medical personnel and health care providers across settings.

The task force also discussed the Oklahoma report card from Last Acts on advance directives, including the items that determined our grade. The report card from Last Acts can be viewed at www.oag.state.ok.us.

The task force recommends:

1. The task force recommends that the powers granted to an agent (attorney in fact) named under the Durable Power of Attorney statute, 58 O.S. 2002, § 1072.1(B)(1) should be clarified to include end-of-life decision-making. These are powers that the health care proxy named under the Advance Directive for Health Care law has now.

In order to clarify these end-of-life decision-making powers, the task force will seek a series of Attorney General Opinions. (See Appendix)

2. The task force recommends that an Attorney General's Opinion be sought to determine whether the nationally-known "Five Wishes" advance directive can be considered as "substantially in the same form" as the Oklahoma Advance Directive for Health Care.

3. The task force recommends that the Task Force and the attorney general's office work with other state agencies and groups to create a consumer guide to end-of-life decision-making in Oklahoma and distribute it widely to consumers and health care providers.

4. The task force recommends that the task force and the attorney general's office, with the assistance of other agencies and groups, create an educator's guide with standardized educational material about Oklahoma's advance decision-making laws, to be developed as lay person's or teacher's guide for those who assist consumers.

5. The task force recommends that the existing Public Guardian Law be funded by legislative appropriation, and pledges its support of efforts to obtain that funding.

6. The task force recommends that Internet access to Oklahoma advance directive forms be streamlined and cross-referenced among state government web sites, such as the attorney general's office and the Department of Human Services, so that consumers can easily find forms and information.

Section Two:

Nursing Facilities



Providing the Best Care to Nursing Home Residents

In 2003, 28.2 percent of deaths of persons 65 and older in Oklahoma occurred in a long-term care setting. Of all deaths in Oklahoma in 2003, 22 percent occurred in nursing facilities.

The Task Force looked at deaths in long term care facilities to respond to the attorney general's charge to the Task Force: Do Oklahomans who die in such facilities have their wishes known and honored? Do they receive competent care, including palliative care?

INTRODUCTION

Today, the population of residents in nursing facilities is older and sicker than in the past. A high percentage of the population suffers from dementia. Many have no surviving family, and although residents of nursing homes sometimes improve and leave the facility, for most it will be their home until they die. The average nursing home stay has fallen from four years to 18 months. Many patients live in nursing facilities less than six months before they die.

In Oklahoma, facilities are regulated by the Oklahoma State Department of Health (OSDH), which surveys facilities for compliance with federal and state regulations. Other agencies with a role in monitoring facilities are the Long-Term Care Ombudsman in the Department of Human Services and the Attorney General's Medicaid Fraud Control Unit.

The focus of nursing facility care under federal regulation is "reaching or maintaining the highest practicable level of functioning." This focus can be interpreted to be in conflict with care at the end of life when the patient or surrogate wishes to withhold or withdraw life-sustaining medical treatment and turn instead to palliative care.

Palliative care, sometimes called comfort care, gives attention to physical symptoms and also social, emotional and spiritual needs as death approaches. The focus is on comfort rather than cure, and accepts that as one nears death, one's functioning will decline.

When people enter nursing facilities and have decision-making capacity, they are asked about their end-of-life preferences and advance directives. Unfortunately many who enter have not completed advance directives and no longer have the capacity to do so. For residents who lack capacity, there may be no one legally empowered to serve as their surrogate. For those with no family members, the facility staff and medical director may have to make decisions with no information from the resident or

anyone else. In cases where a serious decision, such as surgery, is an option, the facility may consult with the staff of Adult Protective Services in the Department of Human Services.

THE TASK FORCE MEETING

The Task Force heard from four panelists:

Marie Bernard, M.D., Chair, Reynolds Department of Geriatric Medicine ; member, Board of Nursing Home Administrators

Connie Stacy, R.N., Director of Clinical Services, Grace Living Centers

Dorya Huser, long-term care, Oklahoma State Department of Health

Esther Houser, Long-Term Care Ombudsman, Department of Human Services

Issues raised by panelists included:

- Because residents of nursing facilities often enter in serious physical debilitation and illness, with limited or no ability to communicate and with inadequate information from prior medical records or family accompanying them, it is difficult for facility staff to ascertain their wishes for end-of-life care.
- Because so many residents suffer from Alzheimer's Disease or other dementias which rob them of their capacity to direct their own care, it is especially important to provide appropriate end-of-life care. Medical research data reveals that insertion of feeding tubes in end-stage dementia patients is associated with more rapid death than not placing the tube. Better results have occurred with allowing patients to eat only their favorite foods and having one-to-one personal interactions at mealtime. A patient with end-stage dementia who refuses to eat may be actively dying. Forcing food and fluids at this time creates discomfort for the patient due to excess fluid accumulation, abdominal distention and difficulty breathing.
- Nursing facility staff believe strongly in their focus of care on rehabilitation and maintenance of function. Thus they may be reluctant to refer a resident for hospice or consider the switch from curative to palliative care. They may feel they have failed, or that they are "giving up." Education is needed to help staff realize their important role in ensuring the residents can have a good death as well as a good life in the nursing facility. Access to ethics committees would be beneficial in helping staff resolve questions.
- An example was given of a nursing facility being cited by surveyors despite having cooperation from a resident's guardian to withdraw hydration from the dying resident. The point was made that surveyors support the right of residents to choose or refuse care, but staff must follow the physician's orders.
- Nursing facilities must satisfy federal regulatory requirements, but also try to determine the point at which to begin palliative care.
- Training given to certify physicians as medical directors of nursing facilities contains no end-of-life content. Training in end-of-life care should be enhanced for facility administrators and other staff as well.

- There is no uniform tool to communicate all the important information when patients transfer from home or from facility to facility.
- Increasingly, residents of nursing facilities who are terminal are served by hospice staff coming into the facility. While this often works well, some believe there is often a breakdown in communication between hospice and the facility. Also, having numerous hospices providing services can cause confusion in the facility. However, there was criticism of the practice at some facilities of restricting residents to only one hospice provider. In some cases there is confusion over which provider is ultimately responsible for the resident, resulting in what one panelist referred to as "turf wars."
- Facility residents have rights, and even if they have some dementia, they often retain enough capacity to discuss their wishes. One panelist stated that far too little effort is expended to ascertain resident wishes.

DISCUSSION

Discussion and questions from the task force and advisory committee were spirited and heated. Some points that were raised included:

- Nursing home staff and state regulators need to develop guidelines for care plans at the end of life.
- Because the physician may have never known the resident except as incapacitated and because many people have made no legal directive or named a proxy, it is difficult to meet the requirements for such a care plan.
- Education of all staff is a never-ending process because of high staff turnover.
- The question was asked as to what recourse a family had if a surveyor required a facility to provide care which, in the family's view, was contrary to the wishes of the resident and family.
- Facilities, under federal regulation, must maintain a resident's highest practical well-being, unless directed otherwise in a legal manner. It was pointed out that operationally this hinges on the interpretation of "well-being." Does it mean having medical technology used to prolong life regardless of quality and perhaps prolong the dying process? Or does it mean having a peaceful, comfortable death?
- Comment was made by a judge that Oklahoma law regarding artificial nutrition and hydration is so restrictive it can be described as "feeding tube forever."
- Because the law setting up public guardians has never been funded, there are no advocates for residents who have no family.
- Other issues raised included training volunteer chaplains, difficulty in determining a terminal prognosis for some conditions, the need to increase the percentage of residents with advance directives, the need to document resident wishes in their

records and the need for educational materials about feeding tubes, CPR and similar issues.

The staff of the OSDH feels they are required to follow federal law that does not always allow flexibility. Families, aging advocates and other providers express frustration that the survey process is preventing residents and families from having a "good death" and instead prolonging the dying process unnecessarily.

The task force recommends:

1. The task force recommends that training in end-of-life care, including pain management, palliative care and special needs of advanced dementia patients be required for staff of licensed nursing facilities. Training is recommended as follows:

- A. In the required continuing education for licensed nursing home administrators.
- B. As part of the continuing medical education requirements for physicians serving as medical directors for nursing facilities.
- C. As a requirement for directors of nursing during their first year of employment.
- D. As a requirement for licensed nurse employees.
- E. As a requirement in the training and continuing education for Certified Nurse Aides (CNA) and Certified Medication Aides (CMA).
- F. As a requirement for social service and/or activity director staff including particular focus on assisting residents with advance directives.

2. The task force recommends the attorney general's office and members of the task force work with nursing facility staff and health department surveyors to develop resources for medical directors and nursing homes including indicators for changing the plan of care at the end of life. The groups should specifically address topics including advanced dementia patients, guidelines for writing an individualized end-of-life plan of care for residents, following resident and family wishes and palliative care measures.

3. The task force recommends that nursing facilities be required to provide a choice of at least two hospices, and three if available in the service area, to residents.

4. The task force recommends that the Oklahoma Department of Health require that licensed nursing facilities have access to a healthcare ethics committee as a resource for support and guidance in end-of-life care issues.

5. The task force will support efforts to increase funding for the Oklahoma Department of Health for these new responsibilities.

Section Three:

Hospitals



Studies Show Patients Want to Die at Home

In 2003, 48.6 percent of Oklahoma deaths occurred in hospitals. The task force focused on the charge from Attorney General Edmondson as it relates to hospitals:

For Oklahomans who die in hospitals, are their wishes known and honored? Do they receive competent care, including palliative care?

INTRODUCTION

In 1989, 85 percent of Oklahomans died in a hospital. In 2003, the percentage had dropped below 50 percent. Although many Oklahomans, mirroring a national trend, want to die at home, surrounded by friends and family and as comfortable as possible, nearly half still die in the hospital.

Hospitals are designed to save lives and the equipment, procedures and attitudes of the staff reflect that goal. When the goals of care move from cure to comfort, the equipment is often un-needed and the predominant procedures and staff attitudes may become a barrier to good care and symptom relief.

The change in reimbursement for hospital care by third-party payers also affects where patients die. Palliative care can often be delivered in other settings that are less costly.

THE TASK FORCE

The Task Force heard from four panelists:

Dennis Martin, R.N., Director, Inpatient Oncology, OU Medical Center

Ken Blank, Director of Chaplain Services, Oklahoma City VA Medical Center

Krista Reyna, R.N., Clinical Nurse Specialist, Mercy Health Center

Diane Gasparra, M.D., Directive, Palliative Care, Mercy Health Center

Panelists focused their remarks on the experience of dying in a hospital Intensive Care Unit (ICU), the challenges for families and staff of switching the goals of care from cure to comfort, the role of the physician in the change in goal of care, the role of chaplains, the role of a palliative care service in a hospital and the importance of communication in determining the goals of care.

- . Death in the ICU was described by a panelist: "It is often very cold, harsh, very technical, extremely messy, oftentimes loud, sometimes hostile, usually impersonal and almost always void of friends and family members. . . One of the first activities that takes place is the family members and the close friends are ushered out. . . and they sit and. . . hope and pray. This is a common scenario that happens sometimes unexpectedly and, very often, quite predictably because the illness or injuries were considered incompatible with life."
- . The advances in medicine, added to the hope of a miracle, cause many families, especially in cases where no advance directive clarifies the patient's wishes, to ask physicians to "do everything possible" to prevent a patient's death. It is difficult to find the appropriate time and way to suggest that the time has come to stop or change the treatment.
- . Physicians are inadequately trained to give bad news. They may perceive referral to hospice or palliative care as "giving up" or failure. They fear that informing the patient that there is no further point in curative treatment will rob them of hope, and they also fear litigation from family members.
- . A key role for chaplains in hospital care is to help people die. This is especially important because most people have little experience talking about death or dying. Chaplains are listeners. They also can be effective as a third party in conferences when the patient and family are so overwhelmed they don't hear everything the physician says.
- . Several hospitals in Oklahoma now have a palliative care service. Palliative care focuses on alleviating pain and other symptoms of suffering and attends to the spiritual, emotional and psycho-social needs of the patient and family. It recognizes that helping patients achieve a peaceful death is one of the most important and rewarding services that a healthcare professional can provide.
- . Palliative care is not limited to work with the terminally ill. It plays an important role in treating the chronically ill and those with life-shortening or life-threatening disease, and is most effective when begun early. This new approach is not universally accepted by physicians and nurses who are unfamiliar with it. The primary association of palliative care with hospice causes some to reject it because they are not dying.
- . For those patients who die in a hospital, a palliative care service is likely to increase the chances that their pain will be managed. When the focus of treatment is on cure, the tests and treatments may cause or increase pain and discomfort. If cure is not possible, such unneeded discomfort should be avoided.
- . Conversations with patients and families are essential in clarifying the goals of treatment. Such conversations are not to direct the patient or family to sign a DNR or take any specific course of action. Instead, the conversation allows for questions about treatments, about probable outcomes and about the understanding of what the doctors have said. By listening to the family and patient and answering questions, the

professional helps them work through the decision-making. The result may be a request for a change in the goal of care.

DISCUSSION

The task force and advisory committee engaged the panelists in questions and discussion.

- . It was noted that for end-of-life conversations to happen earlier and more often in hospitals, someone must be willing to take the risk to initiate the conversation. It takes courage and skill.
- . Nationally, fewer than 15 percent of patients who are resuscitated survive to leave the hospital. For the frail elderly, fewer than five percent will survive.
- . Palliative care programs decrease referrals to hospital ethics committees. One Task Force member noted that about 80 percent of ethics committee consults are actually communication problems. Also, re-admission rates to the hospital and length-of-stay indicators decrease.
- . It was noted by several participants that members of ethnic or racial minority groups may have culturally diverse expectations about end of life. At times, the conversation must involve a person outside the family, such as a minister. Translators may not understand the medical terminology or culture.
- . In our culture, we praise those who are seen to "fight" death rather than accept it peacefully. Thus, language and social norms have to be modified to help us accept the goal of comfortable, peaceful death.
- . Residents of long-term care facilities who wish to die at in the facility are too often transferred to hospitals because administrators fear regulators and litigation or because of lack of end-of-life education.
- . Participants aired various views about the professional most responsible for initiating end-of-life conversations. Those favoring physicians cited the essential understanding of health issues and care options but admitted the time pressures on contemporary physicians make it difficult. Those favoring attorneys found them fully competent to prepare advance directives and discuss the complicated legal and medical issues involved.
- . The 1991 Patient Self-Determination Act mandates all health care agencies to inform patients of their rights in end-of-life care and assist them to complete advance directives if they wish to do so.

The task force recommends:

1. The task force recommends that the Oklahoma Hospital Association appoint a special committee to work with the task force to implement the following in Oklahoma hospitals:

- A. The Oklahoma Hospital Association include programs related to palliative care for adults and children in their annual conferences.
- B. Hospitals implement palliative care programs throughout their facilities extending from ICU through extended care units for adults and children.
- C. Hospitals enhance their response to the Patient Self Determination Act beyond the admitting process by having trained staff contact every patient and assist in preparation of advance directives if desired.
- D. Hospitals endorse nurse certification/specialty curriculum for palliative care by insuring at least one nurse with such training is on the staff. If children are part of the population, this training should include pediatric-focused content.
- E. Hospitals use their Quality Improvement programs to implement and measure improvements in end of life care, including pain management, use of advance directives, and related issues.
- F. Hospitals include end-of-life issues in competence measures for R.N.s in appropriate settings.
- G. Hospitals develop policies so a patient's properly executed "Oklahoma Do-Not-Resuscitate Consent Form" (DNR) is honored.

Section Four:

Hospice Care



Hospice Should be Readily Available, Panelists Say

Each year, more than 700,000 individuals in the United States receive care at the end of life from a hospice. About 28.4 percent of people over age 65 in Oklahoma utilize hospice when they are dying. Because hospice is such a critical piece of good end-of-life care, the task force reviewed hospice services to address the charge from the attorney general:

Does hospice increase the knowledge of my wishes and ensure they are followed? Will I receive competent end-of-life care under hospice?

INTRODUCTION

Hospice services have been available in the U. S. since 1974. The hospice movement has been lauded for providing a better death experience for patients and families by allowing them to die at home, by focusing on palliative rather than curative care to ensure comfort and by caring for the emotional and spiritual needs of the patient and the family.

Medicare added a hospice benefit in 1982, and hospice is covered by many insurance policies. Forty-seven states and the District of Columbia currently include hospice as a Medicaid benefit.

THE TASK FORCE MEETING

The Task Force heard from panelists on several major concerns, including:

- What barriers exist to providing hospice care to a larger proportion of patients?
- Are there concerns over the quality of care in some hospices?

The Task Force heard from panelists:

Mary Lee Warren, Director, Judith Karman Hospice, Inc.

Terry Gonsolin, Director, Oklahoma Hospice Association

Mary Quisenberry, M.S.W., retired social worker, Deaconess Hospital

Gary Johnson, M.D., University of Oklahoma College of Medicine

Barriers to hospice care were noted by several panelists, including:

- . Hospice benefits under Medicare are often misunderstood or there are different interpretations of them. For example, the requirement that a patient be expected to die in six months or less to qualify makes it difficult to determine when some patients might be eligible. Cancer patients have a somewhat predictable trajectory or pattern of decline, so can be deemed to be within six months of death more easily. Patients with pulmonary disease, heart disease, renal failure and others have a more uncertain timeline and prognosis.
- . There is some confusion about the scope of benefits under hospice. Hospice should provide all types of comfort care, but some hospices may not provide the full range of compensable services. Although hospice generally does not cover curative treatment such as artificial nutrition and hydration, chemotherapy, radiation therapy or diagnostic tests, all of these could be part of a hospice service if their purpose was patient comfort.
- . Oklahoma does not have a hospice benefit under Medicaid, one of only a few states not to provide coverage. Hospice care might actually save Medicaid dollars if it were available.
- . For a person to die at home, hospice generally requires an in-home caregiver. If there is no caregiver, hospice may not be able to provide services.
- . Some ethnic or racial groups are unfamiliar with hospice. Cultures differ in their acceptance of services at the end of life. Some may resist the change from curative to palliative care, or believe that suggestions of such a change are a form of discrimination against them.
- . Families not educated about hospice would often like to change the direction of care but do not know how to do so.
- . Physicians are often reluctant to refer a patient for hospice. As noted in prior sessions, physicians are inadequately educated on end of life and in communication skills to discuss death with patients and families. The timing uncertainty for some diseases, as described above, also prevents some referrals. Physicians often believe that the only favorable patient outcome is cure. This death-denying attitude means the physician cannot accept the loss of a patient that is implied in a referral to hospice.
- . Concerns about the regulation of hospices to ensure quality of care were raised by some panelists. One concern was the proliferation of hospices, up to about 120 hospice organizations in the state. Most of the growth has been in proprietary, or for-profit, hospices. The proliferation has led to a competition for patients which one panelist termed "cut-throat." Fierce competition has allegedly led to unethical business practices and declining quality of care.

Examples cited included:

- .. limiting the amount of Medicare money to be spent per patient, per day
- .. giving bonuses to nurses who keep patient costs down
- .. admitting patients who do not meet Medicare eligibility criteria
- .. discharging patients whose care becomes too expensive
- .. refusing patients whose care is more complicated and expensive
- .. limiting nursing visits or ancillary services
- .. falsifying bereavement and volunteer programs
- .. offering payment to doctors for referrals.

The Task Force learned that such instances have been reported and action has already been initiated on these concerns.

The proliferation of hospices makes referrals complex as well. One panelist noted that at one time there were 52 providers in central Oklahoma, making it difficult to keep track of them.

DISCUSSION

Members of the task force and the advisory group discussed the points above.

One new point raised and clarified was the oversight of hospices by the Oklahoma State Department of Health. Because of lack of state and federal funding, the Department may only survey hospices every seven years unless there is a complaint lodged. It was noted that hospice scrutiny is very lax compared to that of nursing facilities.

Despite the large number of hospices, few are equipped to serve pediatric patients. Pediatric issues at end of life include the reluctance of physicians to refer children to hospice and the lack of training for pediatricians in end-of-life care.

The task force recommends:

1. The task force recommends that oversight of hospices in Oklahoma be strengthened and enhanced. Oklahoma State Department of Health responsibilities should be expanded in the following ways:

A. All new hospices should be surveyed by the Oklahoma State Department of Health within six months of their initial licensing.

B. All licensed hospices should be surveyed by the Oklahoma State Department of Health at least every two years.

C. The Oklahoma State Department of Health, in cooperation with hospice associations, should develop a required certification program for all hospice administrators and patient care coordinators.

D. The Oklahoma State Department of Health should develop a survey to measure family satisfaction with care received by all discharged hospice patients, the results of which to be submitted to the OSDH.

E. The Oklahoma State Department of Health should require data reporting from all licensed hospices and make the information available to the public in the hospice annual report, and also as an Oklahoma State Department of Health website report card, including information such as referral source, number of admissions, date of admission and discharge, reason for discharge, primary diagnosis, age, race, gender, marital status, payment type and full disclosure and identification of ownership.

2. The task force will support efforts to increase funding for the Oklahoma State Department of Health for these new responsibilities.

3. The task force recommends that a state hospice advocate or ombudsman program be created outside the hospice licensing agency.

4. The task force recommends that the task force work with the Oklahoma Health Care Authority to expand and simplify Medicaid coverage for hospice care including hospice care for children.

Section Five:

Children



End-of-Life Issues Affect People Old and Young

The impending, inevitable death of a child is unimaginable to most parents, but this tragic situation occurs for hundreds of Oklahoma families each year. Whether related to congenital conditions, injury or disease, children can encounter the same suffering and prolongation of the death as adults.

INTRODUCTION

The task force considered the special barriers to ensuring that children, who cannot execute advance directives or other legal documents making their wishes known, receive quality health care near the end of life.

For Oklahoma's children who die in hospitals, are their wishes known and honored? Do they receive competent care including palliative care?

THE TASK FORCE MEETING

The Task Force heard from four panelists:

Carole Kenner, DNS, RNC, FAAN, Dean of the Oklahoma University College of Nursing

Roger Sheldon, M.D., Oklahoma University College of Medicine

Kevin Donovan, M.D., M.L.A., Oklahoma Bioethics Center

DISCUSSION

On behalf of the panelists, Dr. Sheldon summarized the panel presentation as follows:

The task force recommends that some of the same protections be available to children as to adults when going through their last days.

While adults can make their personal wishes known to others by way of conversations, advance directives and healthcare proxies, children by definition lack the legal status and often the capacity to decide for themselves. Decisions for children will have to be made by others-surrogate decision-makers.

Surrogates can make decisions with the guidance of:

- formal statements signed by the patient (living wills or advance directives)
- a more subjective understanding of the patient's attitudes and wishes (recalled conversations)
- substituted judgment based on an informed concept of what the patient typically would have done faced with a similar situation, and finally,
- independently determining the best interests of the patient.

Only the last approach applies to infants and toddlers.

In most cases we can rely on the parents and other close family members to provide the guidance for doctors and nurses in these final days. Virtually all parents have the best interests of their children at heart. Even when other children or burdensome financial issues exist, most families can be relied upon to do the best thing for the child in extremis. In addition, we can typically accept that the child, upon maturity, would likely adhere to the mores and values of the family. Thus the family can speak for the child in matters of treatment and comfort.

Emotional comfort, spiritual support and pain relief should be provided to all persons who are dying. Attention to a child's pain with expert management of that pain is increasingly available in hospitals and chronic care facilities. The same expertise should reach into the home and the hospice, assuring that pain is not an issue for the dying child. The emotional support is best offered by the child's family assisted by sensitive professionals assuring that the child will not be separated from loved ones. The family will determine the appropriate involvement of clergy and pastoral care professionals in bringing spiritual well-being to child and family alike.

If the child is over the age of understanding, around 7 to 8-years-old, it is best to bring the child into the discussion of the proper treatments. While the child may not be mature enough to understand all the treatment decisions, some form of assent (if not full consent) is advisable to take the child's own experience into account. Teenage children may have an even greater competence to participate in planning their care or indicate their readiness to forego treatments.

Infants and toddlers are incapable of participating in their care planning, but as a class, they should not be excluded from the humane protections we want for ourselves. Children, including newborn infants, should, by reason of their minority, be neither more nor less likely to be afforded the protections of end-of-life care as adults.

Children should not be forced to endure futile especially inhumane treatments or prolongation of death where the parents or guardian and medical advisors agree on reduction in treatments. Neither should they have care inappropriately withheld for lack of full and complete information. Therefore we need the utmost accuracy in diagnosis and prognosis in order that good predictions can be made. In situations where the prediction of death in the near future is not clear-cut, more time and better information should be sought.

In that rare situation where the parents and the physicians disagree on the best course, ethics committees, experts and clergy can serve as useful sounding boards to clarify thinking on either side of the question.

Where the family holds on tighter than may seem best for the child, religious and health care professionals may want to review the child's prognosis again with the family, but ultimately family wishes should be honored. Where the family wants to reduce or discontinue care in the face of a reasonable hope of improvement or survival, child protective services and the statutes provide for protection of the child. Initially health professionals will need to speak out for the child in this situation. A guardian ad litem may be needed to speak for the child and argue his rights.

Many of these childhood deaths will take place in the hospital or chronic care facility. These institutions must be sensitive to the needs of the child and family, providing for comfort where cure is not an option and supporting the family both before, during and after the death with the best in diagnosis, prognosis and care planning, appropriate psychological and pastoral care services, and bereavement support of the highest sensitivity and cultural competence.

Hospice services should be available to assist the non-hospitalized child and family through these difficult times. These services should be covered under Medicaid and insurance plans. This connection to experienced professionals will ease the problems of pain relief, psychological and spiritual support and managing the ongoing illness. Forgoing treatments or attempts at cure should not be a pre-condition for receiving hospice services. Services should be available more than six months in advance of the expected death.

Education programs for professionals and all hospice personnel should be readily available to enhance systems for children and meet their special needs.

Many of these suggestions are drawn from the Institute of Medicine's comprehensive report, "When Children Die" which should be considered by all those interested in this subject. Digests from this publication are available at <http://www.nap.edu/openbook/0309084377/html/>.

The task force recommends:

1. The task force recommends that the task force and the attorney general's office work with other state agencies and groups to create a consumer/parent guide to all advance decision-making regarding adults, newborns, children, and their families in Oklahoma. The guide should address issues of guardianship, assent and the need for letters to protect the family of a dying child from potential investigation.
2. The task force recommends that hospitals, hospices, and other institutions that care for seriously ill or injured adults or children should work with physicians, parents, patients including children, psychologists, and other relevant experts to create policies and procedures for involving adult and child patients in discussions and decisions about their medical condition and its treatment.

These policies and procedures should be sensitive to adult and children's intellectual and emotional maturity and preferences and to families' cultural backgrounds and values. While adults can make their personal wishes known to others by way of conversations, advance directives and healthcare proxies, children by definition lack the legal status and often the capacity to decide for themselves. Decisions for children and other citizens without decision-making capacity will have to be made by surrogate decision-makers.

3. The task force recommends that training in neonatal/pediatric end-of-life care including pain management, and palliative care, be required for all staff of facilities that provide medical care for children and their families.
4. The task force recommends that a resource center for pediatric palliative and end-of-life care be established.

Appendix

Additional Resources and Information

Issues for Further Study:

The task force will conduct further study of the Do-Not-Resuscitate Form mandated by the Oklahoma Do Not Resuscitate Act, 63 O.S. 2004, § 3131.5 and its use and effectiveness in health care facilities.

The task force will conduct further study to see whether a hierarchy of decision-makers, or some other decision-making process is needed when a patient is incapacitated and no advance directive exists.

The task force will conduct further study of the Artificial Nutrition and Hydration for Incompetent Patients Act, 63 O.S. 2004, § 3080.1, et. seq., and its use and effectiveness in health care facilities.

The task force will conduct further study of state-sponsored Internet-based registries where advance directives can be registered and easily retrieved when needed by health care providers.

The task force will conduct further study of the needs of patients with Alzheimer's and other dementias regarding end-of-life issues.

The task force will conduct further study to assist health care professionals to determine when the end of life is near and palliative care is appropriate by use of guidelines that exist in medical literature for diagnosing terminal prognoses for non-cancer conditions such as Chronic Obstructive Pulmonary Disease, Congestive Heart Failure, Alzheimer's and other dementias.

The task force will conduct further study of end-of-life issues and hospice in assisted living facilities and other long-term care settings.

The task force will conduct further study regarding hospice in assisted living facilities.

The task force will conduct further study regarding coordination of care between hospices and nursing homes.

The task force will conduct further study of the actions of the Advisory Council on Pain Management to see whether there are pain management issues that should be considered by the task force at a later date.

The task force will conduct further study to gather Oklahoma data regarding use of advance directives in end-of-life care and other issues. The task force will consider publishing a state report card similar to the Last Acts national report card.

The task force will conduct further study of the end-of-life and palliative care content in the curriculum of health care professional schools in Oklahoma.

The task force will conduct further study on other special populations as it continues its work, including but not limited to:

- Persons with Alzheimer's Disease and other dementias
- Persons with developmental disabilities and chronic disability
- Inmates in the custody of the Department of Corrections
- Culturally diverse populations
- Persons with mental illness

Additional AG Opinion Requests

- A.** Does the Durable Power of Attorney statute, 58 O.S. 2002, § 1072.1(B)(1), include authority for the agent (attorney in fact) to make decisions regarding life-sustaining treatment decisions on behalf of the principal if the language required for appointment of a health care proxy under the Oklahoma Rights of the Terminally Ill or Persistently Unconscious Act is included in the durable power of attorney document?
- B.** Does the Durable Power of Attorney statute, 58 O.S. 2002, § 1072. 1 (B)(1), include authority for the agent (attorney in fact) to make decisions regarding withholding or withdrawing artificial nutrition and/or hydration on behalf of the principal if the language required for appointment of a health care proxy under the Oklahoma Rights of the Terminally Ill or Persistently Unconscious Act, including a specific question about artificial nutrition and hydration, is included in the durable power of attorney document?
- C.** Does the Durable Power of Attorney statute, 58 O.S. 2002, § 1072.1(B)(1), which complies with the requirements and includes the language required for appointment of a health care proxy under the Oklahoma Rights of the Terminally Ill or Persistently Unconscious Act, require witness by a notary public to authorize the agent (attorney in fact) to make life-sustaining treatment decisions on behalf of the principal?

If the Attorney General's Opinion requests regarding the clarification of powers of the Durable Power of Attorney are answered in the negative, the Task Force may consider legislation at a later date.

If the Attorney General's Opinion requests regarding the clarification of powers of the Durable Power of Attorney are answered in the positive, the Task Force will work with the Department of Human Services, Aging Services Division, to incorporate the necessary changes into the existing DHS DPOAHC recommended form.

Additional Policy Recommendations

HOSPICE

The task force recommends that public and private insurers should restructure hospice benefits for adults and children to:

Add hospice care to the services required by Congress in Medicaid and other public insurance programs for adults and children and to the services covered for adults and children under private health plans;

Eliminate eligibility restrictions related to life expectancy, substitute criteria based on an adult's or child's diagnosis and severity of illness, and drop rules requiring adults or children to forgo curative or life-prolonging care (possibly in a case management framework); and

Include outlier payments for exceptionally costly hospice patients.

The task force recommends that in addition to modifying hospice benefits, Medicaid and private insurers should modify policies restricting benefits for other palliative services related to an adult's or child's life-threatening medical condition. Such modifications should:

Reimburse the time necessary for fully informing and counseling families of adult patients, parents (whether or not the child is present) about their family member or child's (1) diagnosis and prognosis, (2) options for care, including potential benefits and harms, and (3) plan of care, including end-of-life decisions and care for which the family is responsible;

Make the expertise of palliative care experts and hospice personnel more widely available by covering palliative care consultations;

Reimburse bereavement services for surviving spouses and family, parents and surviving siblings of children who die; and

Specify coverage and eligibility criteria for palliative inpatient home health, and professional services based on diagnosis (and, for certain services, severity of illness) to guide specialized case managers and others involved in administering the benefits.

CHILDREN

The task force recommends Federal and state Medicaid agencies, professional, specialty, and pediatric organizations, and private insurers cooperate to (1) define diagnosis and, as appropriate, severity criteria for eligibility for expanded benefits for palliative, hospice, and bereavement services for children; (2) examine the appropriateness for reimbursing pediatric

palliative and end-of-life care of diagnostic, procedure, and other classification systems that were developed for reimbursement of adult services; and (3) develop guidance for practitioners and administrative staff about accurate, consistent coding and documenting of palliative, end-of-life, and bereavement services.

The task force recommends that public and private organizations, including philanthropic organizations, should collaborate to improve the collection of descriptive data, epidemiological, clinical, organizational, and financial to guide the provision, funding, and evaluation of palliative, end-of-life, and bereavement care for children and families.

The task force recommends that organizations that fund pediatric oncology, neonatal, and similar clinical and research centers or networks should define priorities for research in pediatric palliative, end-of-life, and bereavement care. Research should focus on infants, children, adolescents, and their families including siblings, and should cover care from the time of diagnosis through death and bereavement. Priorities for research include but are not limited to the effectiveness of:

Clinical interventions, including symptom management;

Methods for improving communication and decision-making;

Innovative arrangements for delivering, coordinating, and evaluating care, including interdisciplinary care teams and quality improvement strategies; and

Different approaches to bereavement care.

The task force recommends the establishment of a public/private partnership to set standards for pediatric palliative and end of life care, and identify other Oklahoma resources.

End-of-Life Care for Late-Stage Alzheimer's Patients

By Betty Garrett Wood, JD

Four million Americans, including approximately 70,000 Oklahomans, have Alzheimer's disease or a related dementia. One in ten persons over the age of 65 years and one in two persons over the age of 85 years have Alzheimer's. The longer a person lives, the higher the chances of developing Alzheimer's. As Oklahoma's population ages, the number of Oklahomans with Alzheimer's is projected to grow to 100,000 by 2025. By 2050, 14 to 16 million Americans are anticipated to be diagnosed with Alzheimer's, unless a cure is found soon.

Now Alzheimer's is the 8th leading cause of death in America. One-half of all nursing home residents are dementia patients. Advanced dementia patients have special needs in end-of-life care. Care should focus on palliative care (not curative care) by providing comfort, managing pain, preventing skin sores and good bowel and bladder care. Advanced Alzheimer's patients may have difficulty or be unable to speak or recognize loved ones, may have difficulty swallowing, may experience weight loss, may have lost the ability to control bowel and bladder, may have lost the ability to walk and may be anxious or scared.

ADVANCE PLANNING

Persons diagnosed with Alzheimer's are not foreclosed from planning ahead. Many patients diagnosed with early to mid-stage Alzheimer's are capable of understanding the concepts and remembering the facts crucial to making the important decisions involved with advanced planning, including appointment of a designated decision-maker and choosing the type of end-of-life care desired by the patient, among other decisions. All persons, but especially persons diagnosed with early to mid-stage dementia, should be urged by their health care provider to make arrangements for having their decisions, whatever they may be, made legally binding. People with Alzheimer's have the moral and legal right to limit or forgo medical life-sustaining treatment and artificial administration of nutrition and hydration. A person with Alzheimer's may not retain the ability to drive, handle financial affairs or live independently in the community, but he or she may still possess the ability to make decisions regarding where they will live and what kind of care they will receive or reject.

It is usually only in the late mid to advanced stages of the disease that a patient will be unable to make decisions for him/herself with regard to the personal decisions, such as place of residence and medical care. And it is only in the advanced stages that a patient may become terminal due to Alzheimer's.

With the possible future dramatic increase in Alzheimer's patients, it is even more imperative to plan ahead so that (1) end-of-life care can be improved to attend to the special needs of advanced dementia patients and (2) persons who are diagnosed with early stage(s) Alzheimer's (with the support of their families and loved ones) may take steps early in the disease process to let their personal wishes and preferences be known in a legally binding way.

For an individual with Alzheimer's disease, advance planning is essential to fulfilling end-of-life wishes. The Alzheimer's Association advocates care providers to facilitate early communication with all older patients to understand their end-of-life wishes.

It is strongly encouraged that a recommendation be considered to provide education for health care providers including but not limited to physicians, nurses, certified nurse aids and nursing home administrators, management and staff; clergy; attorneys; and families regarding advance planning, rights of patients and the special needs of Alzheimer's patients at the end of life (especially regarding pain management and tube feeding issues).

If there is no advance planning by a dementia patient, the Alzheimer's Association advocates palliative care for advanced dementia patients, believing that efforts at life extension create burdens and avoidable suffering.

PAIN MANAGEMENT

With the functional impairments that arise with Alzheimer's, it may be impossible for an Alzheimer's patient, especially one in the advanced stages of the disease, to communicate with words to the health care provider that the patient feels pain. Pain assessment may be complicated by a number of factors in a person with dementia - she/he may have difficulty finding the right word to describe pain, may not be able to think abstractly to communicate degree of pain as a number on a scale or as a facial expression on a visual pain scale, may have difficulty identifying site of pain, may not be aware or forget that an as-needed pain medication is available, may forget about pain if not feeling it at that time, may report pain less as impairment worsens, and may have hearing or sight problems, among other impairments. So, the provider must look for non-verbal clues that the patient is in pain. For example, certain facial expressions, body language and movement, vocalizations, lack of appetite, and/or change in attitude or usual behavior, among others, may be indications of pain.

Pain in older adults is often under-treated and can lead to a worsening of dementia symptoms. It is important to be aware of signs of pain and to anticipate pain that may be caused by existing and known health conditions (which are not uncommon in older patients) such as arthritis, common cold, infections, falls, broken bones, prostate problems, and other long-term medical conditions. In 2000, 42.5 percent of Oklahoma nursing home residents were found to experience persistent severe pain, according to Brown University Center for Gerontology and Health Care Research. Given that nursing home residents with Alzheimer's have difficulty reporting pain, it is likely that the percentage actually experiencing severe pain is much more. It is imperative that pain assessment and management be improved for Alzheimer's patients.

It is strongly encouraged that a recommendation be adopted to require nursing home management and staff to be trained in best practices in pain assessment and management in Alzheimer's patients.

It is strongly encouraged that a recommendation be adopted urging the Department of Health nursing home inspectors/surveyors to give priority attention to evidence of appropriate pain assessment and management in Alzheimer's patients.

FEEDING TUBE/ASSISTED ORAL FEEDING

In 2000, the Ethics Advisory Panel of the Alzheimer's Association moved to a firm recommendation of assisted oral feeding coupled with hospice care when needed as the compassionate alternative to tube feeding for the advanced Alzheimer's patient. Tube feeding is associated with increased diarrhea and related discomfort, and with increased use of physical restraints to keep patients from pulling out the tube, even at a time when most long-term care facilities recognize the benefits of minimal or no restraint policies. Nutritional status does not usually improve with tube feeding, nor does use of a feeding tube prevent or lower the incidence of aspiration pneumonia. There is no evidence to suggest that tube feeding reduces skin breakdown or the likelihood of pressure sores. Moreover, tube feeding is contrary to the preferences of an overwhelming number of elderly.

A person receiving tube feeding is denied the gratification of tasting preferred foods, which may be one of the only (if not the only) pleasant activity remaining to that person.

It is strongly encouraged that a recommendation be adopted to require nursing home management and staff to be trained in best practices with regard to tube feeding and assisted oral feeding in advanced Alzheimer's patients.

It is strongly encouraged that a recommendation be adopted to urge Department of Health nursing home inspectors/surveyors to give priority attention to the special needs of Alzheimer's patients with regard to tube feeding and assisted oral feeding.

GUIDELINES FOR TERMINAL DIAGNOSIS

According to the Centers for Medicare and Medicaid Services (CMS) Manual, Alzheimer's disease and related disorders may support a prognosis of six months or less under many clinical scenarios. The identification of specific structural/functional impairments, together with any relevant activity limitations, should serve as the basis for palliative interventions and care planning. These impairments and limitations associated with a primary diagnosis of Alzheimer's are frequently complicated by co-morbid and/or secondary conditions.

The current CMS guidelines for determining when an Alzheimer's patient is terminal are available at and provide generally that Stage 7 under the Reisberg Functional Assessment Staging (FAST) Scale (including loss of speech, locomotion and consciousness) identifies the threshold of activity limitation that would support a six-month prognosis (without considering the impact of co-morbid and secondary conditions). Ultimately, the combined effects of Stage 7 Alzheimer's and (1) a co-morbid condition (such as clinically significant coronary heart disease or chronic obstructive pulmonary disease) or (2) secondary conditions (such as pressure sores or delirium) should be such that most Stage 7 Alzheimer's patients would have a prognosis of six months or less.

It is strongly encouraged that a recommendation be adopted urging education of health care providers regarding the CMS Guidelines for diagnosing terminal prognosis for dementia to enable more patients with advanced stage Alzheimer's to access hospice care.

Glossary

Advance Directive: A general term describing a variety of legal instructions people can sign ahead of time to express their wishes about medical treatment. Advance directives are sometimes called living wills. In Oklahoma, advance directives include the Oklahoma Advance Directive for Health Care, which combines a living will and a health care proxy; a Durable Power of Attorney for Health Care, and a Do Not Resuscitate (DNR) Consent. The Department of Human Services prints and distributes these documents free of charge. The advance directive can also be found on the Attorney General's website, www.oag.state.ok.us.

Artificial Nutrition and Hydration: When a person can no longer eat or drink by mouth, artificial nutrients and liquids can be given to them by tube, either through their nose or directly into the stomach or intestine. See "tube feeding."

Brain Death: The permanent absence of all brain functions, including those of the brain stem which controls basic functions like reflexes and breathing. When brain death occurs, a person is dead. If they are an organ donor, organs can be recovered after brain-death is pronounced. Brain death is not the same as a Persistent Vegetative State.

Cardiac Arrest: Absence of an effective heartbeat. When the heart stops beating.

Cardiopulmonary Resuscitation (CPR): Efforts to restore breathing and heartbeat to a patient in cardiac or respiratory (breathing) arrest. Typically involves "mouth-to-mouth" and forceful pressure on the chest to restart the heart. May also involve electric shock (defibrillation) or a plastic tube down the throat into the windpipe (intubation).

Coma: A condition lacking both wakefulness and awareness. Comas are typically transient: patients recover, die, or evolve to some other state of impaired consciousness.

Comfort Care: See Palliative Care.

Dementia: A degenerative neurological disorder characterized by a progressive loss of all cognitive functions with some arousal mechanisms remaining normal.

Durable Power of Attorney for Health Care: A document that allows people to name a surrogate decision-maker, called an agent, to speak for them and make medical decisions if they are ill and unable to speak for themselves. In Oklahoma, an agent's ability to make some life-sustaining decisions is uncertain. An agent is allowed to sign a DNR Order.

Do Not Resuscitate (DNR) Order. A physician's order not to perform CPR on a patient. DNR orders are important because providing cardiopulmonary resuscitation, CPR, is the standard of care and is always attempted unless there is a specific DNR order. In Oklahoma, a person can sign a DNR consent for themselves without a physician's order. See Advance Directive.

End of Life: In medical terms, a time when death as a natural result of illness or advanced age is expected within a limited period of time, usually six months to a year.

Health Care Proxy: A document that allows people to name a surrogate decision-maker, called a proxy, to speak for them and make medical decisions when they are terminally ill and are unable to speak for themselves. In Oklahoma the health care proxy is included in the Oklahoma Advance Directive for Health Care document.

Hospice: Care provided to terminally ill patients and their families by an interdisciplinary team, working in conjunction with a physician. Hospice care is aimed at relieving the physical, emotional and spiritual distress that is often part of the dying process. This care, which is a Medicare benefit, can be delivered in the home or in nursing facilities by non-profit or for-profit agencies.

Intubation: Insertion of a tube through a person's airway to get oxygen into the patient's lungs. A person who is intubated cannot speak.

Living Will: A document that addresses what types of medical care people do or do not want to receive when they become terminally ill and are unable to speak for themselves. In Oklahoma the living will is included in the Advance Directive for Health Care document.

Palliative Care: Compassionate care (comfort care) that provides medical, emotional, psychological and spiritual support. The goal is to meet the needs of dying patients by ensuring that medications and other methods for controlling pain are readily available and that other symptoms are also effectively managed. Hospice care is one type of palliative care.

Prognosis: Prediction of the probable outcome of a disease or medical condition.

Respiratory Arrest: The inability to breathe on one's own. When breathing stops.

Terminal Condition: Defined in Oklahoma law as an incurable and irreversible condition that even with the administration of life-sustaining procedures will cause death within six months.

Tube Feeding: A method of artificially delivering liquid and nutrients for patients that cannot eat or drink by mouth. Usually for short-term tube feeding, a long tube, called a nasogastric or "NG" tube, is inserted through the patient's nose and esophagus into the stomach. For long-term feeding, a tube may be inserted directly through the skin into the stomach (a "PEG" tube) or into the intestine (a "J" tube).

Vegetative State: A condition of complete unawareness of self and environment, accompanied by sleep-wake cycles and total or partial preservation of brain functions like heart beat and reflexes. In Oklahoma law this condition is described as "persistently unconscious."

Ventilation/Ventilator: Use of an artificial breathing machine, often called a respirator. A plastic tube is put down the throat to help breathing. A machine pumps air in and out of the lungs through the tube when a person is no longer able to breathe on their own.

Withholding or Withdrawing Treatment: The language of the Advance Directive for Health Care directs physicians and other health care providers to withhold or withdraw treatment if it is only artificially prolonging life. Treatment necessary for comfort or to alleviate pain is continued. It is not true that once a life-sustaining treatment has been started it cannot be stopped.

Additional information on these issues can be found on the attorney general's website at
www.oag.state.ok.us.

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